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ABSTRACT

The report, one of a series describing innovative practices in integrating people with disabilities into community life, describes the Gig Harbor (Washington) group home which serves five severely retarded adults. The home is staffed by five people, two teams and the Director, with each team living in the house on alternate weeks. Topics covered include development of the Neighborhood Living Project which administers the home, the Project's procedures and philosophy (e.g., provision of a long-term home, opportunity to develop and maintain significant relationships, and opportunity to learn and do things for oneself). Also reported are problems the home faces. These include meeting the administrative requirement for extensive data collection which sometimes interferes with informal household routines and complying with state Medicaid regulations which question the placement of some of the residents and raises the issue of program accountability. (DB)

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Center on Human Policy

"GOIN' FOR IT":

LIFE AT THE GIG HARBOR

GROUP HOME

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"Goin' For It":
Life at the Gig Harbor Group Home

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March, 1988

This is one in a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices in integrating people with disabilities into community life.

"Goin' For It": Life at the Gig Harbor Group Home

The staff at the Gig Harbor group home use a particular phrase a lot, "go for it" or "goin' for it." With these words, they encourage the residents to try something new, or to get a chore done. This phrase is always used in a positive sense. It recognizes the effort or determination on the part of a resident to accomplish something. It also symbolizes what the staff does as well. They each bring a certain zest to their work. Although tempered with knowledge and experience, the staff are enthusiastic about their work. They enjoy working with each other and with the men and women who live in the group home.

This report describes the Gig Harbor Group Home as it was when I visited in 1987; since then, many changes have occurred. The report presents some issues worth the consideration of other residential service providers. Thanks to Kathy Easton*, then the Director of this small agency, and all the others for their time and hospitality.

Gig Harbor, Washington

Originally an Indian fishing village, Gig Harbor was "discovered" by a U. S. government surveying party in 1841. The small, protected bay came to support one of the oldest fishing fleets on Puget Sound. Today, Gig Harbor is still a small village, only a ten minute drive northwest from Tacoma. While fishing is still an important industry here, the main source of

*With the exception of Kathy Easton, all of the names used are pseudonyms.

income is tourism. This spot attracts people from Washington, Oregon and Northern California. The village bustles with markets, fish stores, restaurants, bars, and boutiques that sell wine, coffee, cheese and tobacco from around the world.

The Gig Harbor Group Home

The Gig Harbor Group Home is located on Soundview, the main road off the highway that leads into the village. The yard and house are well maintained. The staff explained that they try to keep the house in "...a bit better shape than the neighbors." I have never seen such a luxurious group home. An early newspaper article opposing the establishment of the home complains that the view of Puget Sound would be "wasted" upon the handicapped residents. The house is a large split level with a semi-circular drive and carport. The house is almost total obscured from the road by a thick hedge and several rhododendron bushes.

The main floor contains a large living and dining room (with a fireplace), kitchen, breakfast nook, two bathrooms and two bedrooms. One of the bedrooms is used as an office by the staff and is furnished with a single bed, two desks and a file cabinet. A large greaseboard is up on one wall. Two men share a master bedroom and its adjoining bathroom. A wide and covered porch looks out onto Puget Sound. Straight ahead one can see the Vashon Islands, and Mt. Rainier is visible to the southeast. This view is magnificent and dominates the entire first floor.

The downstairs is finished with two bedrooms, one bathroom, a staff office, and a large recreation room with a brick fireplace. Beyond the recreation room is a small kitchen with a

stove, refrigerator, dishwasher, and so on. Completing the downstairs is a laundry room and furnace area. The recreation room and downstairs kitchen are empty and obviously unused. The staff told me that it is used during the winter for some activities and for dancing when they have parties. A dog, King, also lives at the house and great efforts are taken to ensure that he remains in the backyard or on a leash, and never "on the loose."

The history of Gig Harbor Group Home

A local group of parents and interested individuals formed a board and received funding to start the home through a state-wide initiative. This money was made available to small agencies in order to build or purchase homes to use as community residences for adults with mental retardation.

The group in Gig Harbor planned to obtain a home located on the other side of the village from the current residence. The next door neighbors protested and the group agreed to relocate. Pierce County purchased the home on Soundview Drive through a referendum and leases it to the organization for $1.00 a year. Although there were protests about this new location, the Board convinced the neighbors that the agency deserved a chance. Over the years, the staff and Board members continued their efforts to turn around public opinion by becoming valued neighbors. This explains in part the efforts at maintaining the appearance of the lawns and exterior of the house and keeping King well under control. A Board member told me the following story about the

increase in community acceptance that members of this home have experienced in the community. The home's washing machine and dryer needed to be replaced. A Board member approached the local Lion's Club to ask for a donation. The group agreed to purchase these appliances for the home. A wealthy member of the community said that he would not give the organization $100,000 as he planned to, if they supported the group home. The Lion's Club went through with the donation of the appliances to the group home and lost out on a large gift themselves.

The residents

Despite the public protest, the Gig Harbor Group Home opened in the summer of 1982 when five men and women, all labeled severely retarded, moved in. They are all originally from Gig Harbor or the surrounding area. Most have lived at one of the state's institutions for the mentally retarded. Today, a few of the residents enjoy some contact with their families.

Three men, Colin, Tom, and Ken, and two women, Joanna and Shirley (all pseudonyms), have lived at the home since it opened. All are young adults. Colin and Shirley are still in high school while the other three work at a sheltered workshop in Tacoma. While all of the residents can say a few words, none speak with any facility. Conversation is difficult and one must rely on facial expressions and gestures for communication.

With the exception of Ken, none of the residents have noticeable physical impairments. Ken cannot move his legs easily. He uses a walker or two canes in order to get around,

and occasionally uses a wheelchair for long trips. Shirley is described as having "challenging behaviors." She will scream when she is confused or upset. According to Kathy, this occurs on Thursdays when the staff change shifts and near the end of the school year. Kathy suggests that Shirley likes school and does not want the school year to end.

The men and women who live at the Gig Harbor Group Home are pleasant individuals who seemed to enjoy my visit. They appeared relaxed and comfortable with each other and the staff.

The staff

Typically, five people staff the Gig Harbor Group Home. Two teams of two individuals, with a man and a woman on each team take turns working week-long shifts. Each team moves into the house for one week and then takes the following week off. The staff changeover occurs on Thursdays, when both teams get together with the Director (the fifth staff person) for a three hour meeting.

Without exception, all of the staff wholeheartedly approved of this staffing pattern. They enjoyed the continuity of time with the residents, and the satisfaction of planning and completing a week's worth of activities together. All of the staff felt encouraged to include their family members in a number of activities with the residents. There is a lot of visiting (staff and residents visiting staff people's homes and family members of the staff coming over to the house), joint activities (residents spent a day digging for clams with the parents of one

staff person). All of the staff felt comfortable including their families and friends in outings with the residents nearly every day. Three out of the four staff people that I met have worked at the home since it opened.

Two major staff changes took place during my visit. One person was fired the day before I arrived, and the Director's (Kathy Easton) last day on the job coincided with the last day of my visit. I also visited on a Thursday, the transitional day when the staff change over. Despite these disruptions, the atmosphere of the home felt calm and unruffled. There was no feeling of chaos, just an awareness that change was taking place, but that the essentials of everyday life would continue. This feeling of comfort and "homey-ness" was striking.

Three of the four staff people whom I met were in their mid-twenties to early thirties. The fourth is a mature woman in her mid-forties. There was a balance of youthful energy and hard-earned wisdom among the staff. This combination seemed to work well for the residents. With the exception of Shirley, the residents seemed comfortable with and quite attached to the staff.

The Neighborhood Living Project

The Gig Harbor Group Home opened under the auspices of the Neighborhood Living Project (NLP) and still (as of my visit in 1987) operates under this system. Based at the University of Oregon, the NLP provides one way of managing a group home. The model developed by the NLP stipulates the residential program

itself as well as a staffing pattern, household management system, and a way of recording the skills taught to the residents.

The two staff person team that is on a week and then off a week is stipulated in the NLP procedures manual. So are a bookkeeping system, job descriptions, roles of Board members and other mechanisms for running a household. The NLP model also includes a detailed analysis of all possible activities that a resident might take part in. All of the residents' activities inside and outside of the home are catalogued according to this system. The NLP attempts to provide both direction for the staff and a way to keep them accountable to the Board of Directors. It also defines and measures the skills taught to and learned by the residents. The direction provided in the NLP manual is the way that business gets done at the Gig Harbor Group Home. The NLP procedures are the essential part of the program here. (Note: The NLP data-keeping system is now longer in use.)

The Philosophy of the Gig Harbor Group Home

When I asked Kathy Easton about the philosophy of the home, she replied thoughtfully and at length. It is hard to separate the philosophy of the Gig Harbor Group Home from the world view of Kathy Easton. I came to realize how much of herself she invested in the lives of the men and women who lived in the home and wondered what the atmosphere of the home would be like after she left.

For Kathy Easton, there is no difference between what she thinks the residents need and what she and the other staff try to provide. These are a secure, long-term home for the residents, the opportunity to develop and maintain significant relationships with family and friends, the opportunity to learn and do things for oneself and the availability of assistance and support from the staff in order to accomplish the first three goals. These are the themes of everyday life at the Gig Harbor Group Home.

A long-term home

In response to my question about the philosophy of the home, Kathy started off by telling me,

> We provide a long-term home for the people...as long as they want to live here...we'd advocate for people to stay here unless they indicated that they wanted to move.

Later, she added,

> A real value of the program is that there is residential security with both independence and interdependence, social and physical integration.

After spending time at the home, it is important to emphasize both parts of the phrase, "long-term home." Part of the security is knowing that one won't be asked or required to move to another place. The other part is in building a real home with others. The homeyness and comfort that exists in this home is tangible. The following example illustrates this point. At about 6:30 a.m. on the second day of my visit, Joanna walks into the kitchen. Kathy tells me that Joanna likes to take her time

getting up in the morning. Joanna is wearing a blue housecoat and fluffy blue slippers. Her eyes are barely open. She gets out a coffee mug and walks over to the pot with yesterday's cold coffee in it. She pours herself a cup and then goes to sit down at the table. Seeing this, the two staff people chuckle. One of them says, "Joanna, all you need now is a cigarette and you'd be all set!" Kathy Easton makes a fresh pot of coffee and suggests that Joanna wait for it. She shakes her head no and drains the cup of old coffee. When the fresh pot is done, Joanna gets up and helps herself to another cup. She now makes some toast and sits down for her breakfast.

This scene of someone sleepily groping for coffee was a typical one. I saw others watching TV, going through the newspaper, walking the dog, setting the table, helping prepare a meal, and so on. These actions were not programs, but the routines of an ordinary life. Kathy Easton believes that the security of living in their own home has helped the residents and contributed to the decrease and even complete absence of most of the unacceptable behaviors. She noted that by living in a home that was really theirs, some of the individuals have "blossomed" and taken a great interest in other things.

Building significant relationships

Another aspect of the home's philosophy is the importance of family members and friends in the lives of the residents. The staff go to great lengths to involve and sometimes re-introduce

the men and women in the home to their natural families and to others in the community. Kathy states,

> It is important for the people who live here to have contact with other people who are not paid to be with him...people other than the staff and other residents. All of the people living here need valued interactions with potentially significant people.

Family ties. The staff help people to develop and/or maintain ties with their families. Kathy is clear that these are the most important relationships for the people in the home. She places a lot of emphasis on respecting the values and perspectives of the families. For instance, Ken enjoys extensive contact with his family, attending church with them every Sunday, going to his parents' house for meals and so on. As part of their religious beliefs, they do not want him to drink alcohol or go to places where alcohol is served. Kathy told me that this used to bother her, because he seemed to enjoy going with other residents to restaurants where alcohol was served. Kathy said a friend pointed out that if Ken were not disabled, he probably would still be a member of this church and choose not to drink or be around alcohol. Kathy agreed with this analysis and concluded that it was also important for Ken to remain on good terms with his family. As they thought about Ken, they realized that what he enjoyed was listening to music in public places. Since then, Ken goes to places where there is music but no alcohol.

Ken's family undertakes the responsibility of keeping in touch with him. Joanna, on the other hand, receives a lot of assistance to keep in touch with her mother and grandmother who live in the same county. Joanna used to see them only every three months, but these visits have recently increased, as Joanna's mother is no longer working out of state. Kathy Easton has also taken a personal interest in her, and makes sure that she can visit her family for holidays and a weekend approximately every other month. She is helped to phone her family once or twice a month. As Kathy stated, "We try to encourage other things too...they come here for supper, or just get together for an evening. The last time I went to Seattle for the day, I dropped her off for a daytime visit." Once a week, she helps Joanna pick out cards to send to her family. Kathy and Joanna are close friends. For instance, Kathy shares Joanna's joy when a visit is arranged. But Kathy is adamant that for Joanna, her family are her most important relationships.

Involving Board members. Kathy has asked Board members to get to know the residents by spending time at the house and inviting them out on a regular basis. As she told me, "rather than them always raising money, I want them to socialize with the people who live here, and be seen in the community doing so."

When I interviewed Susan, a Board member, she wanted to talk about the Board's activities and the challenges they face. Kathy Easton obviously wanted her to talk about her relationship with Tom. Susan obliged, and she told me how she and her family first got involved. She had felt badly about the bad press that the

home was getting, so she and her daughter went over one Christmas with some cookies. She started visiting on a regular basis and was asked to join the Board;

> Tom and I got to be closer than the rest. Don't ask me why, it just happened that way. He spends time with my family, for meals, watches football with my husband. He goes to church with us. He goes to soccer games with my husband, they come back here for a beer.

Connections with the staff. The staff at the home are also encouraged to develop warm relationships with the men and women who live in the home. The staff and residents do a lot of things together when the staff are not working. Kathy Easton's friendship with Joanna serves as a model for the others. These two women do a lot of things together on Kathy's personal time, such as going to concerts, out for meals, visit with Kathy's friends and family. Kathy identifies with Joanna when she says, "Joanna and I are genuine friends. I like her, we have similar interests in music, watching people...we enjoy each other."

At the last annual state-wide conference for residential service providers, Kathy and Joanna made a joint presentation about life in the Gig Harbor Group Home. Kathy took slides of the things that went on around the house. Joanna helped her pick out some of the slides and the two of them talked about what each of the slides showed.

Joanna doesn't talk much--only a few words. But it is soon clear to me that she is fond of Kathy Easton. During my visit, people are planning a good-bye party for Kathy. She was recently

given some pink flamingos for her yard at home and brought them in to show everybody at the home. The staff picked out flamingo cards for the invitations for the party. The next time Joanna was out, she dragged a staff person to a store and pointed to an inflatable pink flamingo refrigerator magnet, which she bought, giggling all the while, and presented with a flourish to Kathy. Later, when I asked Joanna if I could take a picture of her in her favorite place, or doing her favorite thing, she chose to be photographed standing next to Kathy Easton.

Involving others. The staff are encouraged to involve their family and friends in all of the activities and parties of this household. The staff can also spend time with their family and friends while on the job--if they include some of the residents. One of the residents attends church with a staff person and her parents, brothers and sisters. This family asked the entire household over to dig for clams and have a picnic supper earlier in the spring. One staff person's girlfriend is a regular visitor to the house and is well liked by the people who live there. As one staff person told me,

> ...we visit my parents, go on picnics with my friends...this makes my life better and I think theirs is better too.

When I asked one person to describe his job to me, he replied,

> It is sharing my life...sharing our lives together. Staff are supposed to share as much of ourselves as we can...even outside the group home. I can lead a normal life--I keep my own contacts and friends and it is great to share it with [the residents].

In this way, the staff integrate their personal and work lives.

Supports from the staff

The staff are expected to play a key role in supporting the people who live at the group home. Kathy expects a lot from her staff, and gets it. Experience in the field of residential services would suggest that week long shifts would tire staff out and render them incapable of doing their jobs. At the Gig Harbor Group Home, the staff prefer this staffing pattern.

Kathy emphasized the importance of the staff in introducing the residents to the daily life of the community. She makes sure that a staff person and one or two residents will have to run an errand in the village everyday. No staff persons can go out to do house business without inviting a resident along. In this way, someone goes out from the house daily to buy groceries, go to the post office, and so on.

What the staff and residents do together is only part of the day's work. There is also a sense of how things should be done. The atmosphere of the home is calm and relaxed. People genuinely seem to enjoy being with each other. The staff and residents also look forward to the days ahead of them with a pleasant anticipation. On one night of my visit, one of the staff, Mavis, and Joanna sat side by side on the couch. Together they went through the paper, Joanna pointing to the pictures and Mavis reading bits and pieces aloud. When they got to the movie pages, Mavis read through all of the ads carefully. Joanna nodded in

response and then pointed to the page with a questioning expression. Mavis replied that a movie on the weekend sounded like a good idea. They smiled at each other and continued to go through the paper.

Many of the residents reputedly engaged in unacceptable behaviors when they first moved into the home. These included smearing feces, screaming, damaging things, hitting oneself. The staff told me that they see very few of these behaviors anymore, and I certainly didn't see any during my visit. Part of the solution rests in the supports offered by the staff to the residents. An alarm clock allows a woman to wake up early each morning, use the bathroom and avoid accidents. The other part of the solution appears to be the language that the staff uses. Nobody "smears feces," but one woman still has a toileting accident on occasion. When another resident screams, the staff readily attribute it to an unwelcome change, such as the upcoming transition of staff, or the school year ending.

A benefit commonly ascribed to community living is the assertion that behavior problems will disappear in more typical settings or that with proper supports and instruction, individuals will stop engaging in the unacceptable activity. While these two factors do make a difference, it also appears true that the perspective of the staff can also make a difference.

In a household where harmony and joint activity are valued, it is not surprising to find that the most frustrating thing for the staff is involving a reluctant resident in the goings on of

the household. For instance, one evening at about 8 p.m., Shirley asked if she could go to bed. The two staff said no and suggested several things that she could do--watch TV, sit in the backyard, listen to music, or join the rest of them for a visit.

Challenges for the program

The staff and Board of the Gig Harbor Group Home work hard to help the residents establish a life for themselves in the community. This task is not without its difficulties and the program faces two challenges. The first deals with the Neighborhood Living Project. The requirement for extensive data collection may interfere with a more informal establishment of household routines and community activities. Second, the interpretation of the state Medicaid regulations questions the placement of some of the residents and raises the issue of program accountability.

Stories and data

As mentioned earlier, the Gig Harbor Group Home uses the NLP materials as a way of organizing the administration and program practices used at the home. The purpose of the NLP is to provide clear guidelines on the running of a residential service for adults with mental retardation. It assumes that residents must be taught a variety of skills and take part in community activities. All of these activities must be recorded and categorized so that the staff can determine the extent of integration that the person is experiencing.

The staff, other professionals and the family of each resident develop an Individual Habilitation Plan (IHP) for each of the five residents. The person is consulted about their own goals and may or may not be at the actual meeting. Typically, only Joanna shows an interest in attending these meetings. During the IHP meeting, a set of goals is established for each of the residents. All of these goals must be "valued activities." This means any activity that is important for the people present at the IHP meeting. Each participant comes to the IHP meeting with suggestions and preferences for the goals. A consensus is reached before any goal is included in the IHP. Kathy Easton describes this as a process of negotiation. "We pick goals that are important--important to the staff, or to the person, or to their family...we strike a balance."

Both "training" and "participation" objectives are developed for each individual during the IHP process. Training goals are set up with the expectation of assistance and instruction from the staff and eventually independent performance of the skill/activity by the resident. Participation is simply exposure to a valued activity where no formal teaching efforts and no expectations of independent performance are made.

Training and participation goals are set up in any of these areas: money management, personal grooming and health care, menus and food preparation and household maintenance. In addition to this, the staff must ensure that each resident takes part in a specified number of "community activities" each week.

These can range from accompanying a staff person on a run for milk, bread or stamps to eating out, visiting others, or going to a movie.

Tagging. The staff follow the NLP's complex data recording system. Commonly referred to as "tagging," the staff keep track of each resident's performance on each of the training activities and participation objectives. On virtually every activity that each resident is engaged in, the staff note whether it was either a training or participation objective, completed with assistance, independently, and so on. For instance, all trips to the community are counted and then coded as physical or social integration. Visits to a variety of generic services (i.e., the physician) are tagged as social integration because the resident is engaged in a conversational exchange with the nurse, doctor and receptionist. I went to the hardware store in order to use the xerox machine. Kathy asked if I would ask Joanna to come with me. At the store, she replied to one of the cashiers who greeted her. Kathy later questioned me about Joanna's interactions and our trip was duly noted as "social integration--non-initiated contact."

A voluminous manual provided by the NLP contains operational definitions for almost any conceivable activity. In this way the formal program is organized and implemented. The staff are fluent in the jargon, and translate all daily activities into coded tags, ready to be counted and matched to program goals. But at Gig Harbor, efforts are made to render this extensive data

collection inconspicuous. The staff do not walk around with clipboards, obviously filling out forms. Nor do any charts grace the walls outside of the office. During the week, the completed tags are placed onto the greaseboard in the office. Every Thursday during the staff meeting, the tags are removed and the information is recorded into the files of each person. The staff claim to use the visual display of tags as a reminder of who needs to complete certain training or participation goals, or who might not be going out of the house enough. Kathy told me that successful trials of ongoing training programs are not recorded. In order to make good use of the staff's time, tags are written up only when a person requires assistance in order to complete a task.

I had many questions about this extensive procedure used to collect and record data. The operational definitions of activities are precise, but I wonder about their actual meaning. For example, physical integration is defined simply as occurring when a person crosses the property line of the residence. By accompanying me to the hardware store, Joanna experienced social integration. A person who goes to his/her parents' house for the weekend is also given one social integration tag. There seems to be qualitative differences between these two instances and what they mean to the person involved. Despite the differences, both activities are considered as one unit of social integration.

The staff expressed frustration that a weekend visit to a parent's home could only be counted as one social and one physically integrating experience. Kathy said that they felt

uncomfortable asking family and friends detailed questions about the activities and experiences of the resident while away. Without the necessary information, they could not accurately record what happened. Kathy asked me about the trip to the hardware store because I "..was more like a staff person than just a visitor." When former staff keep in touch with a resident, and the two develop a friendship, the staff at the group home are more likely to ask them the detailed questions necessary for the NLP system of data collection.

Recording data on the training and participation objectives is the formal way of remembering things at the group home. But there is also an important, informal process of keeping track of the history of the people here. The staff tell many stories about the residents and their lives. One afternoon, two huge photo albums were brought out for my benefit. Surrounded by staff and residents, I went through them both. Practically every picture brought a story, laughter and happy memories. This was not just a collection of photographs put together because all group homes have them, but a real tangible record, a history:

> This part of the world received a large snowstorm last Thanksgiving, and everyone howled at the pictures of them shovelling themselves out, pushing one of the cars up the drive, making a snowman, throwing snowballs.
>
> There was Tom's graduation picture. It was an 8x10 color photograph of Tom in his high school graduation robes standing on the porch with Puget Sound in the background. He was smiling and holding his school attendance

certificate. Mavis sighed with satisfaction as she came to this picture and said, "That is the best picture that I have ever taken...isn't it lovely? Tom was very patient and I took several shots. But he was so proud when he gave an enlarged copy, framed, of it to his parents."

There were several pictures from the open house last Christmas. Kathy told me that in her first year at the home, the Christmas party included people that no one at the home knew very well, but the Board thought it was important that they be invited. For this past year's party she said, "We asked only people we knew and wanted to spend time with. It was a great day. We all had so much fun getting ready for that party."

Another picture in the album shows Tom last October, carving out his first Jack O'Lantern. The face he designed and cut out had a cleft lip, as he does. Mavis and Darrell point this picture out to me and tell me that it is a positive thing, a sign that Tom accepts the way he looks and does not see himself as unusual.

By going through the photo albums, I start to come into the real life of the household. Going through the albums with everyone breaks the ice and stories come tumbling out. The woven paper basket that Susan and her daughter made and brought over. The school snapshot of a young girl on the fridge is Susan's daughter. She has an affectionate place in the lives of the

people here. And tales of past parties are told. Parties are a big deal here, and everyone is disappointed that I can't stay two more days and take part in Kathy's send-off.

I hear of one party that everyone from the house went to. Most people were tired and ready to go home after a couple of hours. But Joanna was dancing and enjoying herself. So Kathy arranged for a friend to bring her home later. I hear about the party Susan and her family held last summer. The barbecue was going and people were eating hamburgers, drinking beer, or dancing. Kathy said,

> All the residents acted just fine--like the people they are. It was a great party. But you must know that some of the neighbors were uncomfortable that Sue and her family invited us. Some of their neighbors didn't come and made it clear that it was because she invited us.

Since then, Sue says, these people have come to know the people in the group home.

The Gig Harbor Group Home has an oral tradition of pictures and stories that document the parties, celebrations, mishaps and triumphs of the people who live there. This history is rich and meaningful--and is not captured on the neat yellow 3M stickums that grace the greaseboard in the home's office. Ironically, it is the latter that fulfills the requirements for accountability and serve as proof that "programming" is taking place.

Program accountability is a serious issue, and funders, parents and advocates are right to be concerned about it. The dilemma all programs face is how to maintain a certain amount of

accountability while also supporting people in active, spontaneous and diverse lives. But when the indicators of a good life must be objectified and measured, as the NLP attempts to do, we must ask ourselves what is being recorded. In a system that equates a trip to the hardware store with a long weekend visit with one's family, the actual experiences of an individual may be lost. The Gig Harbor Group Home is a good program because the people responsible for it are sensitive and caring individuals. While they record behaviors, activities, and events, the process of tagging seems irrelevant to what the place is all about.

It is the stories that bring this program to life. The informal, oral tradition of photos and stories at the home are an important way for people to celebrate and keep track of the meaningful events in their lives. It also creates a shared history for the mentally handicapped individuals who now live with each other, a past to be enjoyed. That these traditions are informal and maintained through desire and not requirement merits emphasis. It would be misleading to think that the spirit of this place could be replicated through tagging or any such approach. It is what the staff bring to their work--the commitment, respect for the residents, sense of humor and the opportunities to join the community that drive this program.

State Medicaid regulations

The issue of program accountability extends further into the lives of the people at Gig Harbor. Involvement with the NLP is a chosen thing. The Board used the NLP model to establish the

home. At any time they can decide to adapt the NLP provisions, or abandon them entirely.* They are required, however, to comply with federal Medicaid regulations as interpreted by state officials. This has been a continuing source of frustration for Kathy Easton and the Board. She claims it is one of the reasons why she is leaving her position.

The continuum of care. The first point of contention is the purpose of the home. The state MR department sees all residents as moving through a continuum of care. They are supposed to move through a succession of residential facilities. Residential services are expected to receive a person, teach him/her a set of skills and then move the person onto the next setting. The more skills a person acquires, the less staff support (and state monies) is needed by the individual. This model of providing services is at odds with the aim of the program's attempts to provide a long-term home for people. Kathy Easton struggles daily with this issue and says that she has resisted the push to move any of the five residents out of the home.

"Self-preservation" skills. Another regulation stipulates that all people living in group homes be able to independently exit from the home in less than ninety seconds once the smoke detector or fire alarm goes off. In order to determine compliance (and funding eligibility), state officials began touring all of the homes across the state and conducting fire drills. Three state fire marshalls showed up unannounced at Gig Harbor one evening at 11:00 p.m. Asking the staff to step

*The home is no longer using the NLP system (Editor's note, 1989).

outside, they triggered the alarm. The residents met the criteria, but had been subjected to daily drills during the "fire drill raids" in order to do so. Kathy worries especially about Ken as he uses canes and this may one day mean his removal to another, more heavily staffed facility.

Perceived interference. Kathy tells me that state officials can make unannounced visits to check on regulation compliance at any time. Because of this, unexpected visitors make the people at the home uncomfortable. As Kathy said, "Only drug dealers live like this. We should not have to."

The extensive tagging and documenting of behaviors, activities and events help the group home meet most of the state's criteria. But reviewers make comments about the training and participation objectives, and suggest other goals or ways of achieving current goals. Ironically, despite extensive programmatic efforts, it is in this area where the staff see real interference by the state. The staff define many of the reviewers' comments as off base. Two of the staff told me the following story as an example.

While reviewers were going over Tom's IHP, they noticed that he had a banking program. The staff were teaching Tom money management skills at naturally-occurring times, such as when they were at the bank or in the store. The reviewers said it wasn't "active treatment" unless it was occurring five days a week, so they suggested that he be taught at home, at the dining table. Gig Harbor staff felt this would not be beneficial, as he would

not generalize the skill to the settings where he would need it. (It should be noted that this interpretation of active treatment is no longer in effect. Now it doesn't matter how often data is kept as long as the data shows how the person is learning. Editor's note, 1989).

The Board's accountability. Kathy and her staff worry about the impact of these state regulations on their work and the lives of the men and women in the home. On the other hand, members of the Board seem more concerned with complying with the regulations. Kathy tells me that the Board does not always support the position she takes on these issues.

The one Board member I met with confirmed Kathy's perspective. Susan defined the three roles of the Board. First, the Board must take care of the residents by providing a good staff, director and keeping the facility maintained. To do that well, Sue insists that Board members must visit the home frequently and have contact with the residents as "friends and neighbors." Second, the Board must be accountable to the community that it is a part of. She suggests that the home is a public responsibility. Ordinary citizens, such as herself, must become involved in the operation of the home. Conversely, the home must give up some privacy and be accountable to the community. Finally, the Board is accountable to the funders. "We need to accept the government regulations. The staff need to learn to accept those regulations and not cry about them all of the time. We are responsible--we do have a liability."

Conclusion

For the five men and women at the Gig Harbor Group Home, the program offers a number of opportunities. These include being treated as individuals worthy of respect and consideration by the staff and Board members. The chance to maintain and/or develop relationships with a variety of people is also provided. Many of the residents have flourished in this particular setting. The stories of their lives are also remembered, cherished and celebrated.

But for all this, there remain some issues that warrant concern. As the agency's name declares, this is still a group home. The Gig Harbor Group Home is a program that receives money from the state. It is subject to state regulations, the interpretation of which can result in drastically different lifestyles for the residents of the home. In its own search for a program structure and accountability, this agency is involved in the Neighborhood Living Project. The predisposition of the program director and the staff are such that the recording of data is not intrusive in the lives of the men and women who live in the home. Kathy Easton's presence as a committed leader in this program is ending. The question that remains unanswered is the effect of her departure on the lives of the men and women who live and work in the home.

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